



**Australian Haemophilia Centre  
Directors' Organisation**

Australian Commission on Safety and Quality in Health Care  
National Safety and Quality Accreditation Standards  
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March 30<sup>th</sup>, 2007

To whom it may concern,

**RE: National Safety and Quality Accreditation Standards discussion paper**

The Australian Haemophilia Centre Directors' Organisation (AHCDO) thanks you for the opportunity to respond to your discussion paper regarding National Safety and Quality Accreditation Standards. AHCDO's members, who are made up of the directors of Haemophilia Treatment Centres (HTC) throughout the country, are at the cutting edge of haemophilia treatment and research in Australia. They have access to detailed information regarding all aspects of the treatment and care of people with haemophilia. By combining and examining this knowledge at a national level, AHCDO continues to be able to offer the best possible consensus and evidence based advice to bodies involved in the welfare of people with haemophilia and other bleeding disorders in Australia.

AHCDO is committed to providing high quality care and safe treatment to patients within the bleeding disorders community. Below are responses to some of the specific questions within the discussion paper.

*It is proposed that a range of regulation, funding and policy levers be used to ensure all health services participate in a registered accreditation and quality process. Which health services should be accredited as a priority, and how can this be best achieved?*

- Accrediting Treatment Centres, or at least registration will help determine where products are being distributed to; at the moment, products are being stored in hospitals which are not HTC's per se, with no knowledge as to the amount being stored or distributed in regional areas particularly.

*It is proposed that Tracer Methodology be implemented in external accreditation reviews. What needs to be done and by whom, to introduce Tracer Methodology in a timely and effective way*

- Haemophilia and other bleeding disorders are genetic; therefore patients have to undergo treatment for their entire lives. The bleeding disorders community specifically has been severely affected by safety and quality issues, with many being infected with HIV and Hepatitis from receiving blood and other products. Research has shown that their quality of life is severely affected by the disease<sup>1</sup>, whilst anecdotal evidence suggests that some patients are reluctant to try advanced treatment options based on past experience.

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<sup>1</sup> Sulser, E. (2006). A patients perspective on haemophilia. *Seminars in Hematology*, 43, Supp 3, S13 – S16.

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- The use of Tracer Methodology within the bleeding disorders community may result in a skewed representation of the quality of care provided, considering the nature of the disease, which needs to be taken into account.

*It is proposed that registration of health care standards become mandatory. What needs to be in place to make this approach feasible?*

- The treatment for Haemophilia varies between patients, as there is still a lot to be learnt about the mechanics of the disease. AHCDO provides guidelines for treatment under certain circumstances based on scientific and anecdotal evidence; however AHCDO appreciates that each clinician needs to take all circumstantial evidence into account before making a decision on treatment.

AHCDO is committed to and conscious of benchmarking and maintaining quality health care in Australia, and is constantly striving to improve patient care and the management and use of blood products.

Please do not hesitate to contact me if you require any further information.

Kind regards,

A handwritten signature in black ink, appearing to read 'V Mrowinski', followed by a vertical red line.

Vicky Mrowinski  
Project Officer  
Australian Haemophilia Centre Directors' Organisation